Figure 2-5a. Annual prevalence of mental/addictive disorders and services for adults
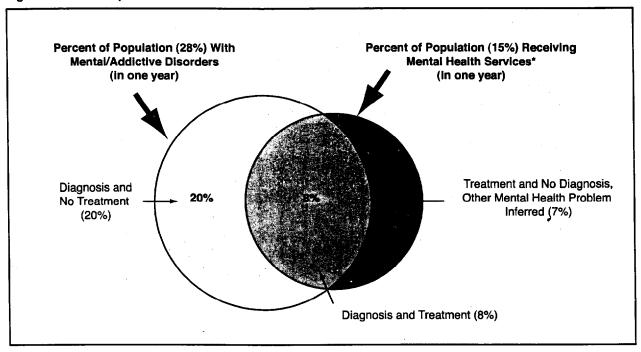

Percent of Population (28%) With Mental/Addictive Disorders (in one year)

Percent of Population (15%) Receiving Mental Health Services* (in one year)

Diagnosis and No Treatment (20%) → 20%

Treatment and No Diagnosis, Other Mental Health Problem Inferred (7%)

Diagnosis and Treatment (8%)

Figure 2-5b. Annual prevalence of mental/addictive disorders and services for adults
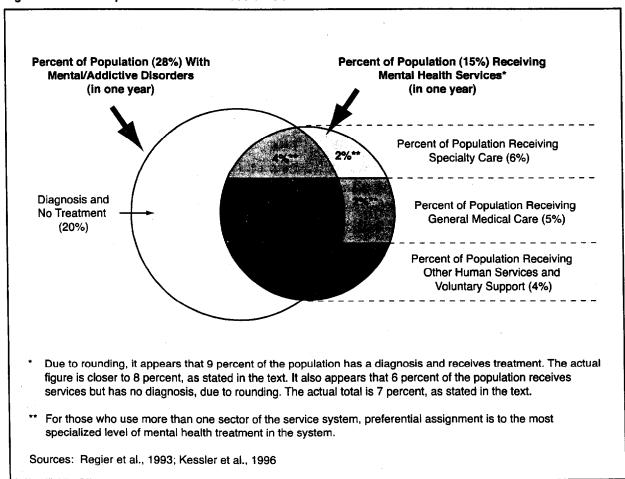

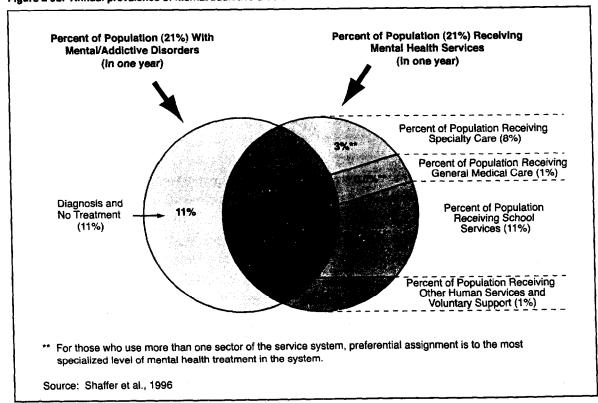**Percent of Population (28%) With Mental/Addictive Disorders (in one year)**

Percent of Population (15%) Receiving Mental Health Services* (in one year)

Diagnosis and No Treatment (20%) →

2%**

Percent of Population Receiving Specialty Care (6%)

Percent of Population Receiving General Medical Care (5%)

Percent of Population Receiving Other Human Services and Voluntary Support (4%)

*   Due to rounding, it appears that 9 percent of the population has a diagnosis and receives treatment. The actual figure is closer to 8 percent, as stated in the text. It also appears that 6 percent of the population receives services but has no diagnosis, due to rounding. The actual total is 7 percent, as stated in the text.

** For those who use more than one sector of the service system, preferential assignment is to the most specialized level of mental health treatment in the system.

Sources: Regier et al., 1993; Kessler et al., 1996

Figure 2-6a. Annual prevalence of mental/addictive disorders and services for children

Percent of Population (21%) With Mental/Addictive Disorders (In one year)

Percent of Population (21%) Receiving Mental Health Services (In one year)

Diagnosis and No Treatment (11%) — **11%**

Treatment and No Diagnosis, Other Mental Health Problem Inferred (11%)

Diagnosis and Treatment (10%)

Figure 2-6b. Annual prevalence of mental/addictive disorders and services for children

Percent of Population (21%) With Mental/Addictive Disorders (In one year)

Percent of Population (21%) Receiving Mental Health Services (In one year)

Diagnosis and No Treatment (11%) — **11%**

3%*

Percent of Population Receiving Specialty Care (8%)

Percent of Population Receiving General Medical Care (1%)

Percent of Population Receiving School Services (11%)

Percent of Population Receiving Other Human Services and Voluntary Support (1%)

** For those who use more than one sector of the service system, preferential assignment is to the most specialized level of mental health treatment in the system.

Source: Shaffer et al., 1996

An era of "moral treatment" was introduced from Europe at the turn of the 19th century, representing the first of four reform movements in mental health services in the United States (Morrissey & Goldman, 1984; Goldman & Morrissey, 1985) (Table 2-10).

The first reformers, including Dorothea Dix and Horace Mann, imported the idea that mental illness could be treated by removing the individual to an asylum to receive a mix of somatic and psychosocial treatments in a controlled environment characterized by "moral" sensibilities. The term "moral" had a connotation different from that of today. It meant the return of the individual to reason by the application of psychologically oriented therapy[19] (Grob, 1994). The "moral treatment" period was characterized by the building of private and public asylums. Almost every state had an asylum dedicated to the early treatment of mental illness to restore mental health and to keep patients from becoming chronically ill. Moral treatment accomplished the former objective, but it could not prevent chronicity.

Shortly after the Civil War, the failures of the promise of early treatment were recognized and asylums were built for untreatable, chronic patients. The quality of care deteriorated in public institutions, where overcrowding and underfunding ran rampant. A new reform movement, devoted to "mental hygiene," began late in the 19th century. It combined the newly emerging concepts of public health (which at the time was referred to as "hygiene"), scientific medicine, and social progressivism. Although the states built the public asylums, local government was expected to pay for each episode of care. To avoid the expense, many communities continued to use local almshouses and jails. Asylums could not maintain their budgets, care deteriorated, and newspaper exposés revealed inhuman conditions both in asylums and local

welfare institutions. State Care Acts were passed between 1894 and World War I. These acts centralized financial responsibility for the care of individuals with mental illness in every state government. Local government took the opportunity to send everyone with a mental illness, including dependent older citizens, to the state asylums. Dementia was redefined as a mental illness, although only some of the older residents were demented. For the past century the states have carried this responsibility at very low cost, in spite of the magnitude of the task.

The reformers of the "mental hygiene" period, who formed the National Committee on Mental Hygiene (now the National Mental Health Association [NMHA]), called for an expansion of the new science, particularly of neuropathology, in asylums, which were renamed mental hospitals. They also called for "psychopathic hospitals and clinics" to bring the new science to patients in smaller institutions associated with medical schools. They opened several psychiatric units in general hospitals to move mental health care into the mainstream of health care. The mental hygienists believed in the principles of early treatment and expected to prevent chronic mental illness. To support this effort, they advocated for outpatient treatment to identify early cases of mental disorder and to follow discharged inpatients.

Treatments were not effective. Early treatment was no more successful in preventing patients from becoming chronically ill in the early 20th century than it was in the early years of the previous century. At best, the hospitals provided humane custodial care; at worst, they neglected or abused the patients. Length of stay did begin to decline for newly admitted inpatients, but older, long-stay patients filled public asylums. The financial problems and overcrowding deepened during the Depression and during World War II.

Enthusiasm for early interventions, developed by military mental health services during World War II, brought a new sense of optimism about

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[19] According to a student of the originator of moral treatment, Philippe Pinel, "moral treatment is the application of the faculty of intelligence and of the emotions in the treatment of mental alienation" (Grob, 1994).

Table 2-10. Historical reform movements in mental health treatment in the United States

Reform Movement	Era	Setting	Focus of Reform
Moral Treatment	1800–1850	Asylum	Humane, restorative treatment
Mental Hygiene	1890–1920	Mental hospital and clinic	Prevention, scientific orientation
Community Mental Health	1955–1970	Community mental health center	Deinstitutionalization, social integration
Community Support	1975–present	Community support	Mental illness as a social welfare problem (e.g., housing, employment)

Sources: Morrissey & Goldman, 1984; Goldman & Morrissey, 1985

treatment by the middle of the 20th century. Again, early treatment of mental disorders was championed and a new concept was born, "community mental health." The NMHA figured prominently in this reform, along with the Group for the Advancement of Psychiatry. Borrowing some ideas from the mental hygienists and capitalizing on the advent of new drugs for treating psychosis and depression, community mental health reformers argued that they could bring mental health services to the public in their communities. They suggested that long-term institutional care in mental hospitals had been neglectful, ineffective, even harmful. The joint policies of "community care" and "deinstitutionalization" led to dramatic declines in the length of hospital stay and the discharge of many patients from custodial care in hospitals.

Concomitantly, these policies led to the expansion of outpatient services in the community, particularly in federally funded community mental health centers. Federal legislation beginning in the mid-1960s fueled this expansion through grants to centers and then through the inclusion of some (albeit limited) mental health benefits in Medicare and Medicaid. The latter was particularly important, because it stimulated the transfer of many long-term inpatients from public mental hospitals to nursing homes, encouraged the opening

of psychiatric units in general hospitals, and ultimately paid for many rehabilitation services for individuals with severe and persistent mental disorders.

The dual policies of community care and deinstitutionalization, however, were implemented without evidence of effectiveness of treatments and without a social welfare system attuned to the needs of hundreds of thousands of individuals with disabling mental illness. Housing, support services, community treatment approaches, vocational opportunities, and income supports for those unable to work were not universally available in the community. Neither was there a truly welcoming spirit of community support for "returning" mental patients. Many discharged mental patients found themselves in welfare and criminal justice institutions, as had their predecessors in earlier eras; some became homeless or lived in regimented residential (e.g., board and care) settings in the community.

The special needs of individuals with severe and persistent mental illness were not being met (General Accounting Office, 1977; Turner & TenHoor, 1978). Early treatment did not prevent disability, although new approaches to treatment would eventually reduce morbidity and improve quality of life. A fourth reform era (1975–present), called the "community support" movement, grew

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directly out of the "community mental health movement." This new reform movement called for an end to viewing and responding to chronic mental disorder only as the object of neglect, by favoring acute treatment and prevention. Reformers advocated for developing "community support systems," with an expanded vision of care and treatment as encompassing the social welfare needs of individuals with disabling mental illness. The emphasis favored the view that individuals could once again become citizens of their community, if given support and access to mainstream resources such as housing and vocational opportunities (Goldman, 1998). At first, mental health treatments were deemphasized in favor of social supports, but newer medications, such as SSRIs and novel anti-psychotic drugs, and more effective psychosocial interventions, such as assertive community treatment for schizophrenia (Chapter 4), facilitated the objectives of community support and recovery in the community.

The voluntary support network expanded with an emphasis on "recovery," a concept introduced by service users, or consumers, who began to take an active role in their own care and support and in making policy. From their inception in the late 1970s, family organizations, such as the National Alliance for the Mentally Ill and the Federation of Families, advocated for services for individuals who are most impaired. As discussed later in this chapter, consumers, who also call themselves "survivors," have formed their own networks for support and advocacy and work with other advocacy groups such as the National Mental Health Association and the Bazelon Center for Mental Health Law.

The de facto mental health system is complex because it has metamorphosed over time under the influence of a wide array of factors, including reform movements and their ideologies, financial incentives based on who would pay for what kind of services, and advances in care and treatment technology. Each factor has been important in its own way. The hybrid system that emerged serves many diverse functions. Unfortunately for those individuals with the most complex needs, and who often have the fewest financial resources, the system is fragmented and difficult to use to meet those needs effectively. Efforts at integrating the service system and tailoring it to those with the greatest needs are discussed, by age group, in subsequent chapters of the report. Many problems remain, including the lack of health insurance by 16 percent of the U.S. population, underinsurance for mental disorders even among those who have health insurance, access barriers to members of many racial and ethnic groups, discrimination, and the stigma about mental illness, which is one of the factors that impedes help-seeking behavior.

Overview of Cultural Diversity and Mental Health Services

The U.S. mental health system is not well equipped to meet the needs of racial and ethnic minority populations. Racial and ethnic minority groups are generally considered to be underserved by the mental health services system (Neighbors et al., 1992; Takeuchi & Uehara, 1996; Center for Mental Health Services [CMHS], 1998). A constellation of barriers deters ethnic and racial minority group members from seeking treatment, and if individual members of groups succeed in accessing services, their treatment may be inappropriate to meet their needs.

Awareness of the problem dates back to the 1960s and 1970s, with the rise of the civil rights and community mental health movements (Rogler et al., 1987) and with successive waves of immigration from Central America, the Caribbean, and Asia (Takeuchi & Uehara, 1996). These historical forces spurred greater recognition of the problems that minority groups confront in relation to mental health services.

Research documents that many members of minority groups fear, or feel ill at ease with, the mental health system (Lin et al., 1982; Sussman et al., 1987; Scheffler & Miller, 1991). These groups experience it as the product of white, European

culture, shaped by research primarily on white, European populations. They may find only clinicians who represent a white middle-class orientation, with its cultural values and beliefs, as well as its biases, misconceptions, and stereotypes of other cultures.

Research and clinical practice have propelled advocates and mental health professionals to press for "linguistically and culturally competent services" to improve utilization and effectiveness of treatment for different cultures. Culturally competent services incorporate respect for and understanding of, ethnic and racial groups, as well as their histories, traditions, beliefs, and value systems (CMHS, 1998). Without culturally competent services, the failure to serve racial and ethnic minority groups adequately is expected to worsen, given the huge demographic growth in these populations predicted over the next decades (Takeuchi & Uehara, 1996; CMHS, 1998; Snowden, 1999).

This section of the chapter amplifies these major conclusions. It explains the confluence of clinical, cultural, organizational, and financial reasons for minority groups being underserved by the mental health system. The first task, however, is to explain which ethnic and racial groups constitute underserved populations, to describe their changing demographics, and to define the term "culture" and its consequences for the mental health system.

Introduction to Cultural Diversity and Demographics

The Federal government officially designates *four* major racial or ethnic minority groups in the United States: African American (black), Asian/Pacific Islander, Hispanic American (Latino),[20] and Native American/American Indian/Alaska Native/Native Hawaiian (referred to subsequently as "American Indians") (CMHS, 1998). There are many other racial or ethnic minorities and considerable diversity within each of the four groupings listed above. The representation of the four officially designated groups in the U.S. population in 1999 is as follows: African Americans constitute the largest group, at 12.8 percent of the U.S. population; followed by Hispanics (11.4 percent), Asian/Pacific Islanders (4.0 percent), and American Indians (0.9 percent) (U.S. Census Bureau, 1999). Hispanic Americans are among the fastest-growing groups. Because their population growth outpaces that of African Americans, they are projected to be the predominant minority group (24.5 percent of the U.S. population) by the year 2050 (CMHS, 1998).

Racial and ethnic populations differ from one another and from the larger society with respect to culture. The term "culture" is used loosely to denote a common heritage and set of beliefs, norms, and values. The cultures with which members of minority racial and ethnic groups identify often are markedly different from industrial societies of the West. The phrase "cultural identity" specifies a reference group—an identifiable social entity with whom a person identifies and to whom he or she looks for standards of behavior (Cooper & Denner, 1998). Of course, within any given group, an individual's cultural identity may also involve language, country of origin, acculturation,[21] gender, age, class, religious/spiritual beliefs, sexual orientation[22], and physical disabilities (Lu et al., 1995). Many people have multiple ethnic or cultural identities.

The historical experiences of ethnic and minority groups in the United States are reflected

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[20] The term "Latino(a)" refers to all persons of Mexican, Puerto Rican, Cuban, or other Central and South American or Spanish origin (CMHS, 1998).

[21] Acculturation refers to the "social distance" separating members of an ethnic or racial group from the wider society in areas of beliefs and values and primary group relations (work, social clubs, family, friends) (Gordon, 1964). Greater acculturation thus reflects greater adoption of mainstream beliefs and practices and entry into primary group relations.

[22] Research is emerging on the importance of tailoring services to the special needs of gay, lesbian, and bisexual mental health service users (Cabaj & Stein, 1996).

in differences in economic, social, and political status. The most measurable difference relates to income. Many racial and ethnic minority groups have limited financial resources. In 1994, families from these groups were at least three times as likely as white families to have incomes placing them below the Federally established poverty line. The disparity is even greater when considering extreme poverty—family incomes at a level less than half of the poverty threshold—and is also large when considering children and older persons (O'Hare, 1996). Although some Asian Americans are somewhat better off financially than other minority groups, they still are more than one and a half times more likely than whites to live in poverty. Poverty disproportionately affects minority women and their children (Miranda & Green, 1999). The effects of poverty are compounded by differences in total value of accumulated assets, or total wealth (O'Hare et al., 1991).

Lower socioeconomic status—in terms of income, education, and occupation—has been strongly linked to mental illness. It has been known for decades that people in the lowest socioeconomic strata are about two and a half times more likely than those in the highest strata to have a mental disorder (Holzer et al., 1986; Regier et al., 1993b). The reasons for the association between lower socioeconomic status and mental illness are not well understood. It may be that a combination of greater stress in the lives of the poor and greater vulnerability to a variety of stressors leads to some mental disorders, such as depression. Poor women, for example, experience more frequent, threatening, and uncontrollable life events than do members of the population at large (Belle, 1990). It also may be that the impairments associated with mental disorders lead to lower socioeconomic status (McLeod & Kessler, 1990; Dohrenwend, 1992; Regier et al., 1993b).

Cultural identity imparts distinct patterns of beliefs and practices that have implications for the willingness to seek, and the ability to respond to,

mental health services. These include coping styles and ties to family and community, discussed below.

Coping Styles

Cultural differences can be reflected in differences in preferred styles of coping with day-to-day problems. Consistent with a cultural emphasis on restraint, certain Asian American groups, for example, encourage a tendency not to dwell on morbid or upsetting thoughts, believing that avoidance of troubling internal events is warranted more than recognition and outward expression (Leong & Lau, 1998). They have little willingness to behave in a fashion that might disrupt social harmony (Uba, 1994). Their emphasis on willpower is similar to the tendency documented among African Americans to minimize the significance of stress and, relatedly, to try to prevail in the face of adversity through increased striving (Broman, 1996).

Culturally rooted traditions of religious beliefs and practices carry important consequences for willingness to seek mental health services. In many traditional societies, mental health problems can be viewed as spiritual concerns and as occasions to renew one's commitment to a religious or spiritual system of belief and to engage in prescribed religious or spiritual forms of practice. African Americans (Broman, 1996) and a number of ethnic groups (Lu et al., 1995), when faced with personal difficulties, have been shown to seek guidance from religious figures.[23]

Many people of all racial and ethnic backgrounds believe that religion and spirituality favorably impact upon their lives and that well-being, good health, and religious commitment or faith are integrally intertwined (Taylor, 1986; Priest, 1991; Bacote, 1994; Pargament, 1997). Religion and spirituality are deemed important because they can provide comfort, joy, pleasure, and meaning to life as well as be means to deal

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[23] Of the 15 percent of the U.S. population that use mental health services in a given year, about 2.8 percent receive care only from members of the clergy (Larson et al., 1988).

with death, suffering, pain, injustice, tragedy, and stressful experiences in the life of an individual or family (Pargament, 1997). In the family/community-centered perception of mental illness held by Asians and Hispanics, religious organizations are viewed as an enhancement or substitute when the family is unable to cope or assist with the problem (Acosta et al., 1982; Comas-Diaz, 1989; Cook & Timberlake, 1989; Meadows, 1997).

Culture also imprints mental health by influencing whether and how individuals experience the discomfort associated with mental illness. When conveyed by tradition and sanctioned by cultural norms, characteristic modes of expressing suffering are sometimes called "idioms of distress" (Lu et al., 1995). Idioms of distress often reflect values and themes found in the societies in which they originate.

One of the most common idioms of distress is somatization, the expression of mental distress in terms of physical suffering. Somatization occurs widely and is believed to be especially prevalent among persons from a number of ethnic minority backgrounds (Lu et al., 1995). Epidemiological studies have confirmed that there are relatively high rates of somatization among African Americans (Zhang & Snowden, in press). Indeed, somatization resembles an African American folk disorder identified in ethnographic research and is linked to seeking treatment (Snowden, 1998).

A number of idioms of distress are well recognized as culture-bound syndromes and have been included in an appendix to DSM-IV. Among culture-bound syndromes found among some Latino psychiatric patients is *ataque de nervios,* a syndrome of "uncontrollable shouting, crying, trembling, and aggression typically triggered by a stressful event involving family. . . " (Lu et al., 1995, p. 489). A Japanese culture-bound syndrome has appeared in that country's clinical modification of ICD-10 (WHO *International Classification of Diseases,* 10th edition, 1993). *Taijin kyofusho* is an intense fear that one's body or bodily functions give offense to others. Culture-bound syndromes

sometimes reflect comprehensive systems of belief, typically emphasizing a need for a balance between opposing forces (e.g., yin/yang, "hot-cold" theory) or the power of supernatural forces (Cheung & Snowden, 1990). Belief in indigenous disorders and adherence to culturally rooted coping practices are more common among older adults and among persons who are less acculturated. It is not well known how applicable DSM-IV diagnostic criteria are to culturally specific symptom expression and culture-bound syndromes.

Family and Community as Resources

Ties to family and community, especially strong in African, Latino, Asian, and Native American communities, are forged by cultural tradition and by the current and historical need to assist arriving immigrants, to provide a sanctuary against discrimination practiced by the larger society, and to provide a sense of belonging and affirming a centrally held cultural or ethnic identity.

Among Mexican-Americans (del Pinal & Singer, 1997) and Asian Americans (Lee, 1998) relatively high rates of marriage and low rates of divorce, along with a greater tendency to live in extended family households, indicate an orientation toward family. Family solidarity has been invoked to explain relatively low rates among minority groups of placing older people in nursing homes (Short et al., 1994).

The relative economic success of Chinese, Japanese, and Korean Americans has been attributed to family and communal bonds of association (Fukuyama, 1995). Community organizations and networks established in the United States include rotating credit associations based on lineage, surname, or region of origin. These organizations and networks facilitate the startup of small businesses.

There is evidence of an African American tradition of voluntary organizations and clubs often having political, economic, and social functions and affiliation with religious organizations (Milburn & Bowman, 1991). African Americans

and other racial and ethnic minority groups have drawn upon an extended family tradition in which material and emotional resources are brought to bear from a number of linked households. According to this literature, there is "(a) a high degree of geographical propinquity; (b) a strong sense of family and familial obligation; (c) fluidity of household boundaries, with greater willingness to absorb relatives, both real and fictive, adult and minor, if need arises; (d) frequent interaction with relatives; (e) frequent extended family get-togethers for special occasions and holidays; and (f) a system of mutual aid" (Hatchett & Jackson, 1993, p. 92).

Families play an important role in providing support to individuals with mental health problems. A strong sense of family loyalty means that, despite feelings of stigma and shame, families are an early and important source of assistance in efforts to cope, and that minority families may expect to continue to be involved in the treatment of a mentally ill member (Uba, 1994). Among Mexican American families, researchers have found lower levels of expressed emotion and lower levels of relapse (Karno et al., 1987). Other investigators have demonstrated an association between family warmth and a reduced likelihood of relapse (Lopez et al., in press).

Epidemiology and Utilization of Services

One of the best ways to identify whether a minority group has problems accessing mental health services is to examine their *utilization* of services in relation to their *need* for services. As noted previously, a limitation of contemporary mental health knowledge is the lack of standard measures of "need for treatment" and culturally appropriate assessment tools. Minority group members' needs, as measured indirectly by their prevalence of mental illness in relation to the U.S. population, should be proportional to their utilization, as measured by their representation in the treatment population. These comparisons turn out to be exceedingly complicated by inadequate under-

standing of the prevalence of mental disorders among minority groups in the United States.[24] Nationwide studies conducted many years ago overlooked institutional populations, which are disproportionately represented by minority groups. Treatment utilization information on minority groups in relation to whites is more plentiful, yet, a clear understanding of health seeking behavior in various cultures is lacking.

The following paragraphs reveal that disparities abound in treatment utilization: some minority groups are underrepresented in the outpatient treatment population while, at the same time, overrepresented in the inpatient population. Possible explanations for the differences in utilization are discussed in a later section.

African Americans

The prevalence of mental disorders is estimated to be higher among African Americans than among whites (Regier et al., 1993a). This difference does not appear to be due to intrinsic differences between the races; rather, it appears to be due to socioeconomic differences. When socioeconomic factors are taken into account, the prevalence difference disappears. That is, the socioeconomic status-adjusted rates of mental disorder among African Americans turn out to be the same as those of whites. In other words, it is the lower socioeconomic status of African Americans that places them at higher risk for mental disorders (Regier et al., 1993a).

African Americans are underrepresented in some outpatient treatment populations, but over-represented in public inpatient psychiatric care in relation to whites (Snowden & Cheung, 1990;

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[24] In spring 2000, survey field work begins on an NIMH-funded study of the prevalence of mental disorders, mental health symptoms, and related functional impairments in African Americans, Caribbean blacks, and non-Hispanic whites. The study will examine the effects of psychosocial factors and race-associated stress on mental health, and how coping resources and strategies influence that impact. The study will provide a database on mental health, mental disorders, and ethnicity and race. James Jackson, Ph.D., University of Michigan, is principal investigator.

Snowden, in press-b). Their underrepresentation in outpatient treatment varies according to setting, type of provider, and source of payment. The racial gap between African Americans and whites in utilization is smallest, if not nonexistent, in community-based programs and in treatment financed by public sources, especially Medicaid (Snowden, 1998) and among older people (Padgett et al., 1995). The underrepresentation is largest in privately financed care, especially individual outpatient practice, paid for either by fee-for-service arrangements or managed care. As a result, underrepresentation in the outpatient setting occurs more among working and middle-class African Americans, who are privately insured, than among the poor. This suggests that socioeconomic standing alone cannot explain the problem of underutilization (Snowden, 1998).

African Americans are, as noted above, overrepresented in inpatient psychiatric care (Snowden, in press-b). Their rate of utilization of psychiatric inpatient care is about *double* that of whites (Snowden & Cheung, 1990). This difference is even higher than would be expected on the basis of prevalence estimates. Overrepresentation is found in hospitals of all types except private psychiatric hospitals.[25] While difficult to explain definitively, the problem of overrepresentation in psychiatric hospitals appears more rooted in poverty, attitudes about seeking help, and a lack of community support than in clinician bias in diagnosis and overt racism, which also have been implicated (Snowden, in press-b). This line of reasoning posits that poverty, disinclination to seek help, and lack of health and mental health services deemed appropriate, and responsive, as well as community support, are major contributors to delays by African Americans in seeking treatment until symptoms become so severe that they warrant inpatient care.

Finally, African Americans are more likely than whites to use the emergency room for mental health problems (Snowden, in press-a). Their overreliance on emergency care for mental health problems is an extension of their overreliance on emergency care for other health problems. The practice of using the emergency room for routine care is generally attributed to a lack of health care providers in the community willing to offer routine treatment to people without insurance (Snowden, in press-a).

Asian Americans/Pacific Islanders

The prevalence of mental illness among Asian Americans is difficult to determine for methodological reasons (i.e., population sampling). Although some studies suggest higher rates of mental illness, there is wide variance across different groups of Asian Americans (Takeuchi & Uehara, 1996). It is not well known how applicable DSM-IV diagnostic criteria are to culturally specific symptom expression and culture-bound syndromes. With respect to treatment-seeking behavior, Asian Americans are distinguished by extremely low levels at which specialty treatment is sought for mental health problems (Leong & Lau, 1998). Asian Americans have proven less likely than whites, African Americans, and Hispanic Americans to seek care. One national sample revealed that Asian Americans were only a quarter as likely as whites, and half as likely as African Americans and Hispanic Americans, to have sought outpatient treatment (Snowden, in press-a). Asian Americans/Pacific Islanders are less likely than whites to be psychiatric inpatients (Snowden & Cheung, 1990). The reasons for the underutilization of services include the stigma and loss of face over mental health problems, limited English proficiency among some Asian immigrants, different cultural explanations for the problems, and the inability to find culturally competent services. These phenomena are more pronounced for recent immigrants (Sue et al., 1994).

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[25] African Americans are overrepresented among persons undergoing involuntary civil commitment (Snowden, in press-b).

Hispanic Americans

Several epidemiological studies revealed few differences between Hispanic Americans and whites in lifetime rates of mental illness (Robins & Regier, 1991; Vega & Kolody, 1998). A recent study of Mexican Americans in Fresno County, California, found that Mexican Americans born in the United States had rates of mental disorders similar to those of other U.S. citizens, whereas immigrants born in Mexico had lower rates (Vega et al., 1998a). A large study conducted in Puerto Rico reported similar rates of mental disorders among residents of that island, compared with those of citizens of the mainland United States (Canino et al., 1987).

Although rates of mental illness may be similar to whites in general, the prevalence of particular mental health problems, the manifestation of symptoms, and help-seeking behaviors within Hispanic subgroups need attention and further research. For instance, the prevalence of depressive symptomatology is higher in Hispanic women (46%) than men (almost 20%); yet, the known risk factors do not totally explain the gender difference (Vega et al., 1998a; Zunzunegui et al., 1998). Several studies indicate that Puerto Rican and Mexican American women with depressive symptomatology are underrepresented in mental health services and overrepresented in general medical services (Hough et al., 1987; Sue et al., 1991, 1994; Duran, 1995; Jimenez et al., 1997).

Native Americans

American Indians/Alaska Natives have, like Asian Americans and Pacific Islanders, been studied in few epidemiological surveys of mental health and mental disorders. The indications are that depression is a significant problem in many American Indian/Alaska Native communities (Nelson et al., 1992). One study of a Northwest Indian village found rates of DSM-III-R affective disorder that were notably higher than rates reported from national epidemiological studies (Kinzie et al., 1992). Alcohol abuse and dependence appear also to be especially problematic, occurring at perhaps twice the rate of occurrence found in any other population group. Relatedly, suicide occurs at alarmingly high levels. (Indian Health Service, 1997). Among Native American veterans, post-traumatic stress disorder has been identified as especially prevalent in relation to whites (Manson, 1998). In terms of patterns of utilization, Native Americans are overrepresented in psychiatric inpatient care in relation to whites, with the exception of private psychiatric hospitals (Snowden & Cheung, 1990; Snowden, in press-b).

Barriers to the Receipt of Treatment

The underrepresentation in outpatient treatment of racial and ethnic minority groups appears to be the result of cultural differences as well as financial, organizational, and diagnostic factors. The service system has not been designed to respond to the cultural and linguistic needs presented by many racial and ethnic minorities. What is unresolved are the relative contribution and significance of each factor for distinct minority groups.

Help-Seeking Behavior

Among adults, the evidence is considerable that persons from minority backgrounds are less likely than are whites *to seek* outpatient treatment in the specialty mental health sector (Sussman et al., 1987; Gallo et al., 1995; Leong & Lau, 1998; Snowden, 1998; Vega et al., 1998a, 1998b; Zhang et al., 1998). This is not the case for emergency department care, from which African Americans are more likely than whites to seek care for mental health problems, as noted above. Language, like economic and accessibility differences, can play an important role in why people from other cultures do not seek treatment (Hunt, 1984; Comas-Diaz, 1989; Cook & Timberlake, 1989; Taylor, 1989).

Mistrust

The reasons why racial and ethnic minority groups are less apt to seek help appear to be best studied

among African Americans. By comparison with whites, African Americans are more likely to give the following reasons for not seeking professional help in the face of depression: lack of time, fear of hospitalization, and fear of treatment (Sussman et al., 1987). Mistrust among African Americans may stem from their experiences of segregation, racism, and discrimination (Primm et al., 1996; Priest, 1991). African Americans have experienced racist slights in their contacts with the mental health system, called "microinsults" by Pierce (1992). Some of these concerns are justified on the basis of research, cited below, revealing clinician bias in overdiagnosis of schizophrenia and underdiagnosis of depression among African Americans.

Lack of trust is likely to operate among other minority groups, according to research about their attitudes toward government-operated institutions rather than toward mental health treatment per se. This is particularly pronounced for immigrant families with relatives who may be undocumented, and hence they are less likely to trust authorities for fear of being reported and having the family member deported. People from El Salvador and Argentina who have experienced imprisonment or watched the government murder family members and engage in other atrocities may have an especially strong mistrust of any governmental authority (Garcia & Rodriguez, 1989). Within the Asian community, previous refugee experiences of groups such as Vietnamese, Indochinese, and Cambodian immigrants parallel those experienced by Salvadoran and Argentine immigrants. They, too, experienced imprisonment, death of family members or friends, physical abuse, and assault, as well as new stresses upon arriving in the United States (Cook & Timberlake, 1989; Mollica, 1989).

American Indians' past experience in this country also imparted lack of trust of government. Those living on Indian reservations are particularly fearful of sharing any information with white clinicians employed by the government. As with African Americans, the historical relationship of forced control, segregation, racism, and discrimination has affected their ability to trust a white majority population (Herring, 1994; Thompson, 1997).

Stigma

The stigma of mental illness is another factor preventing African Americans from seeking treatment, but not at a rate significantly different from that of whites. Both African American and white groups report that embarrassment hinders them from seeking treatment (Sussman et al., 1987). In general, African Americans tend to deny the threat of mental illness and strive to overcome mental health problems through self-reliance and determination (Snowden, 1998). Stigma, denial, and self-reliance are likely explanations why other minority groups do not seek treatment, but their contribution has not been evaluated empirically, owing in part to the difficulty of conducting this type of research. One of the few studies of Asian Americans identified the barriers of stigma, suspiciousness, and a lack of awareness about the availability of services (Uba, 1994). Cultural factors tend to encourage the use of family, traditional healers, and informal sources of care rather than treatment-seeking behavior, as noted earlier.

Cost

Cost is yet another factor discouraging utilization of mental health services (Chapter 6). Minority persons are less likely than whites to have private health insurance, but this factor alone may have little bearing on access. Public sources of insurance and publicly supported treatment programs fill some of the gap. Even among working class and middle-class African Americans who have private health insurance, there is underrepresentation of African Americans in outpatient treatment (Snowden, 1998). Yet studies focusing only on poor women, most of whom were members of minority groups, have found cost and lack of insurance to be barriers to treatment (Miranda & Green, 1999). The discrepancies in findings suggest

that much research remains to be performed on the relative importance of cost, cultural, and organizational barriers, and poverty and income limitations across the spectrum of racial and ethnic and minority groups.

Clinician Bias

Advocates and experts alike have asserted that bias in clinician judgment is one of the reasons for overutilization of inpatient treatment by African Americans. Bias in clinician judgment is thought to be reflected in overdiagnosis or misdiagnosis of mental disorders. Since diagnosis is heavily reliant on behavioral signs and patients' reporting of the symptoms, rather than on laboratory tests, clinician judgment plays an enormous role in the diagnosis of mental disorders. The strongest evidence of clinician bias is apparent for African Americans with schizophrenia and depression. Several studies found that African Americans were more likely than were whites to be diagnosed with schizophrenia, yet less likely to be diagnosed with depression (Snowden & Cheung, 1990; Hu et al., 1991; Lawson et al., 1994).

In addition to problems of overdiagnosis or misdiagnosis, there may well be a problem of underdiagnosis among minority groups, such as Asian Americans, who are seen as "problem-free" (Takeuchi & Uehara, 1996). The presence and extent of this type of clinician bias are not known and need to be investigated.

Improving Treatment for Minority Groups

The previous paragraphs have documented underutilization of treatment, less help-seeking behavior, inappropriate diagnosis, and other problems that have beset racial and ethnic minority groups with respect to mental health treatment. This kind of evidence has fueled the widespread perception of mental health treatment as being uninviting, inappropriate, or not as effective for minority groups as for whites. The Schizophrenia Patient Outcome Research Team demonstrated that

African Americans were less likely than others to have received treatment that conformed to recommended practices (Lehman & Steinwachs, 1998). Inferior treatment outcomes are widely assumed but are difficult to prove, especially because of sampling, questionnaire, and other design issues, as well as problems in studying patients who drop out of treatment after one session or who otherwise terminate prematurely. In a classic study, 50 percent of Asian Americans versus 30 percent of whites dropped out of treatment early (Sue & McKinney, 1975). However, the disparity in dropout rates may have abated more recently (O'Sullivan et al., 1989; Snowden et al., 1989). One of the few studies of clinical outcomes, a pre- versus post-treatment study, found that African Americans fared more poorly than did other minority groups treated as outpatients in the Los Angeles area (Sue et al., 1991). Earlier studies from the 1970s and 1980s had given inconsistent results (Sue et al., 1991).

Ethnopsychopharmacology

There is mounting awareness that ethnic and cultural influences can alter an individual's responses to medications (pharmacotherapies). The relatively new field of ethnopsychopharmacology investigates cultural variations and differences that influence the effectiveness of pharmacotherapies used in the mental health field. These differences are both genetic and psychosocial in nature. They range from genetic variations in drug metabolism to cultural practices that affect diet, medication adherence, placebo effect, and simultaneous use of traditional and alternative healing methods (Lin et al., 1997). Just a few examples are provided to illustrate ethnic and racial differences.

Pharmacotherapies given by mouth usually enter the circulation after absorption from the stomach. From the circulation they are distributed throughout the body (including the brain for psychoactive drugs) and then metabolized, usually in the liver, before they are cleared and eliminated from the body (Brody, 1994). The rate of

metabolism affects the amount of the drug in the circulation. A slow rate of metabolism leaves more drug in the circulation. Too much drug in the circulation typically leads to heightened side effects. A fast rate of metabolism, on the other hand, leaves less drug in the circulation. Too little drug in the circulation reduces its effectiveness.

There is wide racial and ethnic variation in drug metabolism. This is due to genetic variations in drug-metabolizing enzymes (which are responsible for breaking down drugs in the liver). These genetic variations alter the activity of several drug-metabolizing enzymes. Each drug-metabolizing enzyme normally breaks down not just one type of pharmacotherapy, but usually several types. Since most of the ethnic variation comes in the form of inactivation or reduction in activity in the enzymes, the result is higher amounts of medication in the blood, triggering untoward side effects.

For example, 33 percent of African Americans and 37 percent of Asians are slow metabolizers of several antipsychotic medications and antidepressants (such as tricyclic antidepressants and selective serotonin reuptake inhibitors) (Lin et al., 1997). This awareness should lead to more cautious prescribing practices, which usually entail starting patients at lower doses in the beginning of treatment. Unfortunately, just the opposite typically had been the case with African American patients and antipsychotic drugs. Clinicians in psychiatric emergency services prescribed more oral doses and more injections of antipsychotic medications to African American patients (Segel et al., 1996). The combination of slow metabolism and overmedication of antipsychotic drugs in African Americans can yield very uncomfortable extrapyramidal[26] side effects (Lin et al., 1997). These are the kinds of experiences that likely contribute to the mistrust of mental health services reported among African Americans (Sussman et al., 1987).

Psychosocial factors also can play an important role in ethnic variation. Compliance with dosing may be hindered by communication difficulties; side effects can be misinterpreted or carry different connotations; some groups may be more responsive to placebo treatment; and reliance on psychoactive traditional and alternative healing methods (such as medicinal plants and herbs) may result in interactions with prescribed pharmacotherapies. The result could be greater side effects and enhanced or reduced effectiveness of the pharmacotherapy, depending on the agents involved and their concentrations (Lin et al., 1997). Greater awareness of ethnopsychopharmacology is expected to improve treatment effectiveness for racial and ethnic minorities. More research is needed on this topic across racial and ethnic groups.

Minority-Oriented Services

Through employment of minority practitioners and the creation of specialized minority-oriented programs, community-based, publicly supported mental health programs have achieved greater minority representation than are found in other mental health settings (Snowden, 1999). Mental health care providers who are themselves from ethnic minority backgrounds are especially likely to treat ethnic minority clients and have been found to enjoy good success in retaining them in treatment (Sue et al., 1991).

The character of the mental health program in which treatment is provided has proven particularly important in encouraging minority mental health service use. Research has shown that programs that specialize in serving identified minority communities have been successful in encouraging minorities to enter and remain in treatment (Yeh et al., 1994; Snowden et al., 1995; Takeuchi et al., 1995; Snowden & Hu, 1996). Modeled on programs successfully targeting groups of recent immigrants and refugees, minority-oriented programs appear to succeed by maintaining active, committed relationships with community institutions and

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[26] Dystonia (brief or prolonged contraction of muscles), akathisia (an urge to move about constantly), or parkinsonism (tremor and rigidity) (Perry et al., 1997).

leaders and making aggressive outreach efforts; by maintaining a familiar and welcoming atmosphere; and by identifying and encouraging styles of practice best suited to the problems particular to racial and ethnic minority group members. A challenge for such programs is to meet specialized sociocultural needs for clients from various backgrounds. The track record of minority-oriented programs at improving treatment outcomes is not yet clear for adults but appears to be positive for children and adolescents (Yeh et al., 1994).

There is a specialized system of care for Native Americans that provides mental health treatment. The Indian Health Service (IHS) includes a Mental Health Programs Branch; it offers mental health treatment intended to be culturally appropriate. Urban Indian Health Programs also provide for mental health treatment. The IHS Alcohol-ism/Substance Abuse Program Branch sponsors services on reservations and in urban communities through contracts with service providers. Most mental health programs in the IHS focus on screening and treatment in primary care settings. Due to budgetary restraints, IHS is able to provide only limited medical, including mental health, coverage of Native American peoples (Manson, 1998).

Many tribes have moved toward self-determination and, as a result, toward assuming direct control of local programs. When surveyed, these tribal health programs reported providing mental health care in a substantial number of instances, although questions remain about the nature and scope of services. Finally, the Department of Veterans Affairs and many state and local authorities provide specialized mental health programming targeting persons of Native American heritage (Manson, 1998). Little is known about the levels and types of care provided under any of these arrangements.

Cultural Competence

Advocates and policymakers have called for all mental health practitioners to be culturally competent: to recognize and to respond to cultural concerns of ethnic and racial groups, including their histories, traditions, beliefs, and value systems (CMHS, 1998).

Cultural competence is one approach to helping mental health service systems and professionals create better services and ensure their adequate utilization by diverse populations (Cross et al., 1989). It is defined as a set of behaviors, attitudes, and policies that come together in a system or agency or among professionals that enables that system, agency, or professionals to work effectively in cross-cultural situations (Cross et al., 1989). This is especially important because most mental health providers are not racial and ethnic minority group members (Hernandez et al., 1998). Using the term "competence" places the responsibility on the mental health services organization and all of its employees, challenging them all to become part of a process of providing culturally appropriate services. This approach emphasizes understanding the importance of culture and building service systems that recognize, incorporate, practice, and value cultural diversity.

There is no single prescribed method for accomplishing cultural competence. It begins with respect, and not taking an ethnocentric perspective about behavior, values, or beliefs. Three possible methods are to render mainstream treatments more inviting and accessible to minority groups through enhanced communication and greater awareness; to select a traditional therapeutic approach according to the perceived needs of the minority group; or to adapt available therapeutic approaches to the needs of the minority group (Rogler et al., 1987). One effort to promote cultural competence has been directed toward mental health services systems and programs. The Center for Mental Health Services has developed, with national input, a preliminary set of performance indicators for "cultural competence" by which service and

funding organizations might be judged. Cultural competence in this context includes consultation with cross-cultural experts and training of staff, a capacity to provide services in languages other than English, and the monitoring of caseloads to ensure proportional racial and ethnic representation. The ultimate test of any performance indicator will be documented by improvements in care and treatment of ethnic and racial minorities.

Another response has been to develop guidelines that more directly convey variations believed necessary in the course of clinical practice. An appendix to DSM-IV presents clinicians with an Outline for Cultural Formulation. The guidelines are intended as a supplement to standard diagnosis, for use in multicultural environments and for the provision of a "systematic review of the individual's cultural background, the role of the cultural context in the expression and evaluation of symptoms and dysfunction, and the effect that cultural differences may have on the relationship between the individual and the clinician" (DSM-IV).

The Outline for Cultural Formulation covers several areas. It calls for an assessment of cultural identity, including degree of involvement with alternative cultural reference groups; cultural explanations of illness; cultural factors related to stresses, supports, and level of functioning and disability (e.g., religion, kin networks); differences in culture or social status between patient and clinician and possible barriers (e.g., communication, trust); and overall cultural assessment.

Others have focused attention on the process by which mental health practitioners must engage, assess, and treat patients and on understanding how cultural differences might affect that process (Lopez et al., in press). Viewed from this perspective, the task is to maintain two points of view—that of the cultural group and that of evidence-based mental health practice—and strategically integrate them with the aim of valuing and utilizing culture, context, and practice in a way that promotes mental health.

This capacity has a dual advantage. The practitioner comes to understand the problem as it is experienced and understood by the patient and, in so doing, gains otherwise inaccessible information on personal and social reality for the patient, as well as a sense of trust and credibility. At the same time the practitioner is able to plan for and implement an appropriate intervention. It is through a facility and a willingness to switch from a professional orientation to that of the client and his or her cultural group that the clinician is best able to implement guidelines for cultural competence such as those specified in DSM-IV (Mezzich et al., 1996).

In the end, to be culturally competent is to deliver treatment that is equally effective to all sociocultural groups. The treatments provided must not only be efficacious (based on clinical research), but also effective in community delivery. The delivery of effective treatments is complicated because most research on efficacy has been conducted on predominantly white populations. This suggests the importance of both efficacy and effectiveness studies on racial and ethnic minorities.

At present, there is scant knowledge about treatment effectiveness according to race, culture, or ethnicity (Snowden & Hu, 1996). Rarely has research evaluating standard forms of treatment examined differential effectiveness. In fact, the American Psychological Association's Division of Clinical Psychology Task Force, which tried to identify the efficacy of different psychotherapeutic treatments, could not find a single rigorous study of treatment efficacy published on ethnic minority clients (Chambless et al., 1996). Nor have studies been carried out on the efficacy of proposed cultural adaptations of treatment in comparison with standard alternatives. Only as more knowledge is gained will it become possible to mount a full-fledged and appropriate response to racial and ethnic differences in the provision of mental health care.

Rural Mental Health Services

The differences between rural and urban communities present another source of diversity in mental health services. People in rural America encounter numerous barriers to the receipt of effective services. Some barriers are geographic, created by the problem of delivering services in less densely populated rural areas and even more sparsely populated frontier areas. Some barriers are "cultural," insofar as rural America reflects a range of cultures and life styles that are distinct from urban life. Urban culture and its approach to delivering mental health services dominate mental health services (Beeson et al., 1998).

Rural America is shrinking in size and political influence (Danbom, 1995; Dyer, 1997). As a consequence, rural mental health services do not figure prominently in mental health policy (Ahr & Holcomb, 1985; Kimmel, 1992). Furthermore, rural economies are in decline, and the population is decreasing in most areas (yet expanding rapidly in a few boom areas) (Hannan, 1998). Rural America is no longer a stable or homogeneous environment. The farm crisis of the 1980s unleashed a period of economic hardship and rapid social change, adversely affecting the mental health of the population (Ortega et al., 1994; Hoyt et al., 1995).

Policies and programs designed for urban mental health services often are not appropriate for rural mental health services (Beeson et al., 1998). Beeson and his colleagues (1998) list a host of important differences that should be considered in designing rural mental health services. In an era of specialized services, rural mental health relies heavily on primary medical care and social services. Stigma is particularly intense in rural communities, where anonymity is difficult to maintain (Hoyt et al., 1997). In an era of expanding private mental health services, rural mental health services have been predominantly publicly funded. Consumer and family involvement in advocacy, characteristic of urban and suburban areas, is rare in rural America. The supply of services and providers is limited, so choice is constrained.

Mental health services in rural areas cannot achieve certain economies of scale, and some state-of-the art services (e.g., assertive community treatment) are inefficient to deliver unless there is a critical mass of patients. Informal supports and indigenous healers assume more importance in rural mental health care.

Rural mental health concerns are being raised nationally (Rauch, 1997; Ciarlo, 1998; Beeson et al., 1998). Model programs offer new designs for services (Mohatt & Kirwan, 1995), particularly through the integration of mental health and primary care (Bird et al., 1995, 1998; Size, 1998). Newer technology, such as advanced telecommunications in the form of "telemental health," may improve rural access to expertise from professionals located in urban areas (Britain, 1996; La Mendola, 1997; Smith & Allison, 1998). Internet access, videoconferencing, and various computer applications offer an opportunity to enhance the quality of care in rural mental health services.

Overview of Consumer and Family Movements

Since the late 1970s, mental health services continue to be transformed by the growing influence of consumer and family organizations (Lefley, 1996). Through strong advocacy, consumer and family organizations have gained a voice in legislation and policy for mental health service delivery. Organizations representing consumers and family members, though divergent in their historical origins and philosophy, have developed some important, overlapping goals: overcoming stigma and preventing discrimination, promoting self-help groups, and promoting recovery from mental illness (Frese, 1998).

This section covers the history, goals, and impact of consumer and family organizations, whereas the next section covers the process of recovery from mental illness. With literally hundreds of grassroots consumer organizations across the United States, no single organization

speaks for all consumers or all families. In fact, even the term "consumer" is not uniformly accepted. Despite the heterogeneity, these organizations typically offer some combination of advocacy and self-help groups (Lefley, 1996).

Many users of mental health services refer to themselves as "consumers." The lexicon is complicated by objections to the term "consumer." To some, being a consumer erroneously signifies that service users have the power to choose services most suitable to their needs. Those who object contend that consumers have neither choices, leverage, nor power to select services. Instead, some consumers refer to themselves as "survivors" or "ex-patients" to denote that they have survived what they experienced as oppression by the mental health system (Chamberlin & Rogers, 1990). This distinction can best be understood in its historical context.

Origins and Goals of Consumer Groups

The consumer movement arose as a protest in the 1970s by former patients of mental hospitals. Their antecedents trace back to the 19th century, when a handful of individuals recovered enough to write exposés expressing their outrage at the indignities and abuses inside mental hospitals. The most persuasive former patient was Clifford Beers, whose classic book, *A Mind That Found Itself* (1908), galvanized the mental hygiene reform movement (Grob, 1994). Beers was among the founders of the National Committee on Mental Hygiene, an advocacy group that later was renamed the National Mental Health Association. This group focuses on linking citizens and mental health professionals in broad-based prevention of mental illness.

With the advent of deinstitutionalization in the 1950s, increasing numbers of former patients of mental hospitals began to forge informal ties in the community. By the 1960s, the civil rights movement inspired former patients to become better organized into what was then coined the mental patients' liberation movement (Chamberlin, 1995).

Groups of patients saw themselves as having been rejected by society and robbed of power and control over their lives. To surmount what they saw as persecution, they began to advocate for self-determination and basic rights (Chamberlin, 1990; Frese & Davis, 1997). The posture of these early groups was decidedly militant against psychiatry, against laws favoring involuntary commitment, and often against interventions such as electroconvulsive therapy and antipsychotic medications (Lefley, 1996; Frese, 1998). Groups called Alliance for the Liberation of Mental Patients, the Insane Liberation Front, and Project Release met in homes and churches, drawing their membership from those with firsthand experiences with the mental health system. Largely unfunded, they sustained their membership by providing peer support, education about services in the community, and advocacy to help members access services and to press for reforms (Furlong-Norman, 1988).

The book *On Our Own* (1978) by former patient Judi Chamberlin was a benchmark in the history of the consumer movement. Consumers and others were able to read in the mainstream press what it was like to have experienced the mental health system. For many consumers, reading this book was the beginning of their involvement in consumer organizations (Van Tosh & del Vecchio, in press). Early consumer groups, although geographically dispersed, voluntary, and independent, were linked through the newsletter *Madness Network News*, which continued publication from 1972 to 1986. During the same era, the Conference on Human Rights and Against Psychiatric Oppression was established and met annually from 1973 through 1985 (Chamberlin, 1990). In 1978, early consumer groups gained what they perceived as their first official acknowledgment from the highest levels of government. The President's Commission on Mental Health stated that ". . . groups composed of individuals with mental or emotional problems are being formed all over the United States" (President's Commission on Mental Health, 1978, pp. 14–15). To date, racial and ethnic minority

group members are underrepresented within the consumer movement proportionate to their growing representation in the U.S. population. There is a need for more outreach and involvement of consumers representing the special concerns of racial and ethnic minorities.

The advocacy positions of consumers have dealt with the role of involuntary treatment, self-managed care, the role of consumers in research, the delivery of services, and access to mental health services. By 1985, consumer views became so divergent that two groups emerged: The National Association of Mental Patients[27] and the National Mental Health Consumers' Association. The former opposed all forms of involuntary treatment, supported the prohibition of electroconvulsive therapy, and rejected psychotropic medications and hospitalization. The latter organization held more moderate views for improving rather than eschewing the mental health service system (Lefley, 1996; Frese, 1998). Both groups eventually disbanded, but the differences of opinion that they reflected became deeply entrenched.

Self-Help Groups

Self-help refers to groups led by peers to promote mutual support, education, and growth (Lefley, 1996). Self-help is predicated on the belief that individuals who share the same health problem can help themselves and each other to cope with their condition. The self-help approach enjoys a long history, most notably with the formation of Alcoholics Anonymous in 1935 (IOM, 1990). Over time, the self-help approach has been brought to virtually every conceivable health condition.

Since the 1970s, many mental health consumer groups emphasized self-help as well as advocacy (Chamberlin, 1995), although to different degrees. Self-help for recovering mental patients initially emphasized no involvement with mental health professionals. Over time the numbers and types of

self-help groups began to flourish and more moderate viewpoints became represented. Self-help groups assume three different postures toward health professionals: the separatist model, the supportive model that allows professionals to aid in auxiliary roles, and partnership models in which professionals act as leaders alongside patients (Chamberlin, 1978; Emerick, 1990). The focus of groups varies, with some groups united on the basis of diagnosis, such as Schizophrenics Anonymous and the National Depressive and Manic-Depressive Association, whereas others are more broad based.

Chamberlin's influential book and another book by former patients, *Reaching Across* (Zinman et al., 1987), explained to consumers how to form self-help groups. These books also extended the concept of self-help more broadly into the provision of consumer-run services as alternatives (as opposed to adjuncts) to mental health treatment (Lefley, 1996).

Programs entirely run by consumers include drop-in centers, case management programs, outreach programs, businesses, employment and housing programs, and crisis services (Long & Van Tosh, 1988; National Resource Center on Homelessness and Mental Illness, 1989; Van Tosh & del Vecchio, in press). Drop-in centers are places for consumers to obtain social support and assistance with problems. Although research is limited, the efficacy of consumer-run services is discussed in Chapter 4.

Consumer positions also are being incorporated into more conventional mental health services—as job coaches and case manager extenders, among others. The rationale for employing consumers in service delivery—in consumer-run or conventional programs—is to benefit those hired and those served. Consumers who are hired obtain employment, enhance self-esteem, gain work experience and skills, and sensitize other service providers to the needs of people with mental disorders. Consumers who are served may be more receptive to care and have role models engaged in their care (Mowbray et al., 1996).

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[27] Later renamed the Nationa   ivors (Chamberlin, 1995).

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Accomplishments of Consumer Organizations

Consumer organizations have had measurable impact on mental health services, legislation, and research. One of their greatest contributions has been the organization and proliferation of self-help groups and their impact on the lives of thousands of consumers of mental health services. In 1993, a collaborative survey found that 46 state mental health departments funded 567 self-help groups and agencies for persons with mental disabilities and their family members (National Association of State Mental Health Program Directors, 1993). A nationwide directory lists all 50 states and the District of Columbia as having 235 different mental health consumer organizations (South Carolina SHARE, 1995).

On a systems level, the consumer movement has substantially influenced mental health policy to tailor services to consumer needs. This influence is described by consumers and researchers as "empowerment." A concept from the social sciences, empowerment has come to be defined by mental health researchers as "gaining control over one's life in influencing the organizational and societal structures in which one lives" (Segal et al., 1995).

Consumers are now involved in all aspects of the planning, delivery, and evaluation of mental health services, and in the protection of individual rights. One prominent example is the passage of Public Law 102-321, which established mental health planning councils in every state. Planning councils are required to have membership from consumers and families. Having a planning council so constituted is required for the receipt of Federal block grant funds for mental health services. Other Federal legislation required the establishment of protection and advocacy agencies for patients' rights in every state (Chamberlin & Rogers, 1990; Lefley, 1996).

Another significant development has been the establishment of offices of consumer affairs in many state mental health authorities. Offices of consumer affairs are generally staffed by consumers to support consumer empowerment and self-help in their particular states. A recent survey of state mental health authorities identified 27 states as having paid positions for consumers in central offices (Geller et al., 1998). In 1995, the Federal Center for Mental Health Services hired its first consumer affairs specialist.

The consumer movement also has had a substantial influence on increasing the utilization of consumers as employees in the traditional mental health system, as well as in other human service agencies (Specht, 1988; U.S. Department of Education, 1990; Schlageter, 1990; Interagency Council on the Homeless, 1991). Consumers are being hired at all levels in the mental health system, ranging from case manager aides to management positions in national advocacy organizations, as well as state and Federal governmental agencies.

Finally, consumers continue to be involved in research in several ways: as *participants* of clinical research; as *respondents* who are asked questions about conditions in their life; as *partners* in some aspect of the planning, designing, and conducting of the research project with professional researchers in control; and as *independent researchers* who conduct, analyze the data, and publish the results of the research project (Campbell et al., 1993). The past decade has witnessed the blossoming of a vibrant consumer research agenda and the growing belief that consumer involvement in research and evaluation holds great promise for system reform, quality improvement, and outcome measurement (Campbell et al., 1993; Campbell, 1997). In an effort to enhance the active role of consumers and others in the research process, the National Institute of Mental Health is developing a systematic means of including public participants in the initial review of grant applications in the areas of clinical treatment and services research. This innovation follows up on a recommendation made by the Institute of

Medicine and Committee for the Study of the Future of Public Health (1988).

Family Advocacy

The family movement has experienced spectacular growth and influence since its beginnings in the late 1970s (Lefley, 1996). Although several advocacy and professional organizations speak to the needs of families, the family movement is principally represented by three large organizations. They are the National Alliance for the Mentally Ill (NAMI), the Federation of Families for Children's Mental Health (FFCMH), and the National Mental Health Association (NMHA). NAMI serves families of adults with chronic mental illness, whereas the Federation serves children and youth with emotional, behavioral, or mental disorders. NMHA serves a broad base of family members and other supporters of children and adults with mental disorders and mental health problems. Though the target populations are different, these organizations are similar in their devotion to advocacy, family support, research, and public awareness.

Fragmentation and lack of availability of services were motivating forces behind the establishment of the family movement. Deinstitutionalization, in particular, was a cogent impetus for the formation of NAMI. Deinstitutionalization of the mentally ill left families in the unexpected position of having to assume care for their adult children, a role for which they were ill prepared. Another motivating force behind the family movement was the past tendency by the mental health establishment to blame parents for the mental illness in children (Frese, 1998). The cause of schizophrenia, for example, had been attributed to the "schizophrenogenic mother," who was cold and aloof, according to a reigning but now discredited view of etiology. Similarly, parents were viewed as partly to blame for children with serious emotional or behavioral disturbances (Melaville & Asayesh 1993; Friesen & Stephens, 1998).

NAMI was created as a grassroots organization in 1979 by a small cadre of families in Madison, Wisconsin. Since then, its membership has skyrocketed to 208,000 in all 50 states (NAMI, 1999). NAMI's principal goal is to advocate for improved services for persons with severe and persistent mental illness—for example, schizophrenia and bipolar disorder. Its sole emphasis on the most severely affected consumers distinguishes it from most other consumer and family organizations. Another NAMI goal is to transform public attitudes and reduce stigma by emphasizing the biological basis of serious mental disorders, as opposed to poor parenting (Frese, 1998; NAMI, 1999). Correspondingly, NAMI advocates for intensification of research in the neurosciences. Through state and local affiliates, NAMI operates a network of family groups for self-help and education purposes.

NAMI's accomplishments are formidable. The organization has become a powerful voice for the expansion of community-based services to fulfill the vision of the community support reform movement. NAMI has successfully pressed for Federal legislation for family membership in state mental health planning boards. It is a prime force behind congressional legislation for parity in the financing of mental health services. It also has made substantial inroads in the training of mental health professionals to sensitize them to the predicament of the chronically mentally ill. It has promoted "psychoeducation," specific information to family members, usually in small-group settings, about schizophrenia and about strategies for dealing with relatives with schizophrenia (Lamb, 1994). Finally, NAMI has successfully lobbied for increased Federal research funding, and it has set up private research foundations (Lefley, 1996).

Similarly, advocacy by parents on behalf of children with serious emotional or behavioral disturbances has had a compelling impact. Advocacy for children was electrified by the publication of Jane Knitzer's 1982 book, *Unclaimed Children*; shortly afterward, the

National Mental Health Association (NMHA) issued *Invisible Children* (NMHA, 1983), followed by *A Guide for Advocates to All Systems Failure* (NMHA, 1993). Knitzer chronicled the plight of families in trying to access care from disparate and uncoordinated public agencies, many of which blamed or ignored parents. NMHA, a pioneer in the mental health advocacy field, assumed a pivotal role in strengthening the child mental health movement in the 1980s and early 1990s. Over time, the Federation of Families for Children's Mental Health has become another focal point for families, championing family participation and support in systems of care and access to services. The Federation's chapters across the United States offer self-help, education, and networking (FFCMH, 1999). Through the efforts of these groups and individuals, among the most noteworthy accomplishments of the family movement has been the emergence of family participation in decisionmaking about care for children, one of the decisive historical shifts in service delivery in the past 20 years.

Overview of Recovery

Until recently, some severe mental disorders were generally considered to be marked by lifelong deterioration. Schizophrenia, for instance, was seen by the mental health profession as having a uniformly downhill course (Harding et al., 1992). At the beginning of the 20th century, the leading psychiatrist of the era, Emil Kraepelin, judged the outcome of schizophrenia to be so dismal that he named the disorder "dementia praecox," or premature dementia. Negative conceptions of severe mental illness, perpetuated in textbooks for decades by Kraepelin's original writings, dampened consumers' and families' expectations, leaving them without hope. A turnabout in attitudes came as a result of the consumer movement and self-help activities. They mobilized a shift toward a more positive set of consumer attitudes and self-perceptions. Research provided a scientific basis for and supported a more optimistic view of the

possibility of recovering function (Harding et al., 1992). Promoting recovery became a rallying point and common ground for the consumer and family movements (Frese, 1998).

The concept of recovery is having substantial impact on consumers and families, mental health research, and service delivery. Before describing that impact, this section first turns to an introduction and definitions.

Introduction and Definitions

Recovery is a *concept* introduced in the lay writings of consumers beginning in the 1980s. It was inspired by consumers who had themselves recovered to the extent that they were able to write about their experiences of coping with symptoms, getting better, and gaining an identity (Deegan, 1988; Leete, 1989). Recovery also was fueled by longitudinal research uncovering a more positive course for a significant number of patients with severe mental illness (Harding et al., 1992), although findings across several studies were variable (Harrow et al., 1997) (see discussion in Chapter 4).

Recovery is variously called a process, an outlook, a vision, a guiding principle. There is neither a single agreed-upon definition of recovery nor a single way to measure it. But the overarching message is that hope and restoration of a meaningful life are possible, despite serious mental illness (Deegan, 1988; Anthony, 1993; Stocks, 1995; Spaniol et al., 1997). Instead of focusing primarily on symptom relief, as the medical model dictates, recovery casts a much wider spotlight on restoration of self-esteem and identity and on attaining meaningful roles in society.

Written testimonials by former mental patients have appeared for centuries. These writings, according to historian of medicine Roy Porter, "shore up that sense of personhood and identity which they feel is eroded by society and psychiatry" (Porter, 1987). What distinguishes the contemporary wave of writings is their critical mass, organizational backing, and freedom of

expression from outside the confines of the institution. Deinstitutionalization, the emergence of community supports and psychosocial rehabilitation, and the growth of the consumer and family advocacy movements all paved the way for recovery to take hold (Anthony, 1993).

The concept of recovery continues to be defined in the writings of consumers (see Figure 2-7). These lay writings offer a range of possible definitions, many of which seek to discover meaning, purpose, and hope from having mental illness (Lefley, 1996). The definitions do not, however, imply full recovery, in which full functioning is restored and no medications are needed. Instead they suggest a journey or process, not a destination or cure (Deegan, 1997). One of the most prominent professional proponents of recovery, William A. Anthony, crystallized consumer writings on recovery with the following definition:

> . . . a person with mental illness can recover even though the illness is not "cured" . . . . [Recovery] is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993).

It is important to point out that consumers see a distinction between recovery and psychosocial rehabilitation. The latter, which is discussed more extensively in Chapter 4, refers to professional mental health services that bring together approaches from the rehabilitation and the mental health fields (Cook et al., 1996). These services combine pharmacological treatment, skills training, and psychological and social support to clients and families in order to improve their lives and functional capacities. Recovery, by contrast, does not refer to any specific services. Rather, according to the writings of pioneering consumer Patricia Deegan, recovery refers to the "lived experience"

Figure 2-7. Definitions of recovery from consumer writings

Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. . . .The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution (Deegan, 1988, p. 15).

One of the elements that makes recovery possible is the regaining of one's belief in oneself (Chamberlin, 1997, p. 9).

Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort. . .I believe that if we confront our illnesses with courage and struggle with our symptoms persistently, we can overcome our handicaps to live independently, learn skills, and contribute to society, the society that has traditionally abandoned us (Leete, 1989, p. 32).

A recovery paradigm is each person's unique experience of their road to recovery. . . .My recovery paradigm included my re-connection which included the following four key ingredients: connection, safety, hope, and acknowledgment of my spiritual self (Long, 1994, p. 4).

To return renewed with an enriched perspective of the human condition is the major benefit of recovery. To return at peace, with yourself, your experience, your world, and your God, is the major joy of recovery (Granger, 1994, p. 10).

of gaining a new and valued sense of self and of purpose (Deegan, 1988).

Impact of the Recovery Concept

The impact of the recovery concept is felt most by consumers and families. Consumers and families are energized by the message of hope and self-determination. Having more active roles in

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treatment, research, social and vocational functioning, and personal growth strikes a responsive cord. Consumers' harboring more optimistic attitudes and expectations may improve the course of their illness, based on related research from the field of psychosocial and vocational rehabilitation (see Chapter 4). Yet direct empirical support for the salutary, long-term effect of positive expectations, on both consumers and families, is still in its infancy (Lefley, 1997).

The recovery concept likewise is having a bearing on mental health research and services. Researchers are beginning to study consumer attitudes and behavior to attempt to identify the elements contributing to recovery. Though still at an early stage, research is being driven by consumer perspectives on recovery. Consumers assert that the recovery process is governed by internal factors (their psychological perceptions and expectations), external factors (social supports), and the ability to self-manage care, all of which interact to give them mastery over their lives. The first systematic efforts to define consumer perceptions of recovery was conducted by consumers. The Well-Being Project, sponsored by the California Department of Mental Health, was a landmark effort in which mental health consumers conducted a multifaceted study to define and explore factors promoting or deterring the well-being of persons diagnosed with serious mental illness (Campbell & Schraiber, 1989). Using quantitative survey research, focus groups, and oral histories, Campbell (1993) arrived at a definition of recovery that incorporates "good health, good food, and a decent place to live, all supported by an adequate income that is earned through meaningful work. We need adequate resources and a satisfying social life to meet our desires for comfort and intimacy. Well-being is enriched by creativity, a satisfying spiritual and sexual life, and a sense of happiness" (p. 28).

Through semistructured interviews with consumers about recovery, a subsequent study identified the most common factors associated with

their success in dealing with a mental illness. They included medication, community support/case management, self-will/self-monitoring, vocational activity (including school), and spirituality (Sullivan, 1994). Other researchers, also using semistructured interviews, suggested that the rediscovery and reconstruction of a sense of self were important to recovery (Davidson & Strauss, 1992).

These early forays by researchers set the stage for consumer-driven research efforts to identify some of the aspects of recovery. A group of consumers with consultant'researchers developed the Empowerment Scale (Rogers et al., 1997). After testing a 28-item scale on members of six self-help programs in six states, factor analysis revealed the underlying dimensions of empowerment to be (1) self-efficacy–self-esteem; (2) power-powerlessness; (3) community activism; (4) righteous anger; and (5) optimism–control over the future. Other instruments, found to have consistency and construct validity, are the Personal Empowerment Scale, the Organizational Empowerment Scale, and the Extra-Organizational Empowerment Scale (Segal et al., 1995).

Mental health services continue to be refined and shaped by the consumer and recovery emphasis. The most tangible changes in services come from assertive community treatment and psychosocial and vocational rehabilitation, which emphasize an array of approaches to maximize functioning and promote recovery. Consumer interest in self-help and recovery has stimulated the proliferation of interventions for what has been called "illness management" or "self-managed care" for relapse prevention of psychotic symptoms. Illness management training programs now teach individuals to identify early warning signs of relapse and to develop strategies for their prevention. All of these transformations in service delivery and research affirming their benefits are discussed at length in Chapter 4.

Champions of recovery assert that its greatest impact will be on mental health providers and the

future design of the service system. They envision services being structured to be recovery-oriented to ensure that recovery takes place. They envision mental health professionals believing in and supporting consumers in their quest to recover. In a groundbreaking article, William A. Anthony described recovery as a guiding vision that "pulls the field of services into the future. A vision is not reflective of what we are currently achieving, but of what we hope for and dream of achieving. Visionary thinking does not raise unrealistic expectations. A vision begets not false promises but a passion for what we are doing."

Conclusions

The past 25 years have been marked by several discrete, defining trends in the mental health field. These have included:

1. The extraordinary pace and productivity of scientific research on the brain and behavior;
2. The introduction of a range of effective treatments for most mental disorders;
3. A dramatic transformation of our society's approaches to the organization and financing of mental health care; and
4. The emergence of powerful consumer and family movements.

Scientific Research. The brain has emerged as the central focus for studies of mental health and mental illness. New scientific disciplines, technologies, and insights have begun to weave a seamless picture of the way in which the brain mediates the influence of biological, psychological, and social factors on human thought, behavior, and emotion in health and in illness. Molecular and cellular biology and molecular genetics, which are complemented by sophisticated cognitive and behavioral science, are preeminent research disciplines in the contemporary neuroscience of mental health. These disciplines are affording unprecedented opportunities for "bottom-up" studies of the brain. This term refers to research that is examining the workings of the brain at the most fundamental levels. Studies focus, for example, on the complex neurochemical activity that occurs within individual nerve cells, or neurons, to process information; on the properties and roles of proteins that are expressed, or produced, by a person's genes; and on the interaction of genes with diverse environmental influences. All of these activities now are understood, with increasing clarity, to underlie learning, memory, the experience of emotion, and, when these processes go awry, the occurrence of mental illness or a mental health problem.

Equally important to the mental health field is "top-down" research; here, as the term suggests, the aim is to understand the broader behavioral context of the brain's cellular and molecular activity and to learn how individual neurons work together in well-delineated neural circuits to perform mental functions.

Effective Treatments. As information accumulates about the basic workings of the brain, it is the task of translational research to transfer new knowledge into clinically relevant questions and targets of research opportunity—to discover, for example, what specific properties of a neural circuit might make it receptive to safer, more effective medications. To elaborate on this example, theories derived from knowledge about basic brain mechanisms are being wedded more closely to brain imaging tools such as functional Magnetic Resonance Imaging (MRI) that can observe actual brain activity. Such a collaboration would permit investigators to monitor the specific protein molecules intended as the "targets" of a new medication to treat a mental illness or, indeed, to determine how to optimize the effect on the brain of the learning achieved through psychotherapy.

In its entirety, the new "integrative neuroscience" of mental health offers a way to circumvent the antiquated split between the mind and the body that historically has hampered mental health research. It also makes it possible to examine scientifically many of the important psychological and behavioral theories regarding normal development and mental illness that have